

Preface

By 2050, 22% of patients are anticipated to live to be 85 years or older and expect to face 3 to 6 years of life with progressive disability (Fried, 2000). This increased longevity, evident in the United States and other industrialized societies, has to large extent been achieved through the technological advances of modern medicine and the development of health maintenance and preventive measures that are at least partially reimbursed for individuals with health care insurance. But as Fried noted, increased longevity comes with a price. More and more patients are living with the complications of chronic illnesses and toward the end-of-life, the patients, their caregivers, the providers involved with their care, as well as the institutions they may reside in, find themselves having to manage multiple physical, psychosocial, spiritual and emotional problems.

In the U.S., the multiple, chronic care needs faced by these patients and their caregivers are often ill served by fragmented systems of care. The current set of health care benefits in the U.S. are, for the most part, designed to meet the needs of patients with acute presentations of individual illnesses and enhance access to surgical and other interventions whose focus is on cure. In the face of payment streams that reward interventional, and single clinical problem oriented approaches to care, health care providers, organizations and payers struggle to create systems of care that can readily accommodate the multidimensional needs of end-of-life patients and their caregivers and support the demanding multidisciplinary team and or case management approaches needed to care for these patients.

As the evidence base that identifies unmet needs for patients approaching the end of their life accumulates and is reported in almost every healthcare setting (Teno, J.M. 2004; Emmanuel, E.J. 2000; Desbiens, N.A), new paradigms for palliative care medicine have emerged. These paradigms of care emphasize the importance of improved quality of life for these patients and their families, enhanced pain and symptom management, improved communication between providers, patients, and caregivers, and recognition of, and provision for, the multidimensional needs of the palliative care patients—needs that are psychosocial, spiritual, that involve greater coordination of

medical and social services, and that offer bereavement services to caregivers after the patient's death. Such paradigms should be made available regardless of anticipated survival times for individuals with progressive chronic medical illnesses and their caregivers (Morrison & Meier, 2004).

In the first four chapters of this book, the contributing authors describe the complexity of clinical needs and barriers that currently exist to the provision of end-of-life care in different health care settings including homecare, acute care and long term residential care. The second set of chapters discuss palliative care in the context of dominant illnesses – Cancer, HIV/AIDS, Chronic Obstructive Lung Disease, Chronic Heart Failure, and Alzheimer's Disease. The next set of chapters focus around the complex needs of children and the elderly, and the last set of chapters address a broader set of issues: how to make the business case for palliative care, how to use Quality Improvement approaches to assess improvements being made in the provision of care, while the last chapter provides a framework for bioethical analyses and dispute mediation in the care of patients and caregivers at the end-of-life.

This book is the beginning of a journey that will need to be refined, and expanded as the American population becomes older as well as more culturally diverse. It is unclear, at this point, how those broad demographic shifts in American will shape the arguments in this book. It is our hope, however, that these arguments will become clearer and that remedies to the fragmented care provided to patients can be found.

All of our contributors have been concerned with improving the care of patients and their caregivers, and we are indebted to each for the time and effort they have put into producing their chapters. They have explored the evidence base for end-of-life care in their individual professional areas and each provided valuable insights which we, and they, hope will result in improved palliative care.

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